



Impact of Spinal Cord Injury in Affective Relationship: A Qualitative Analysis of the Subjects' Perception

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ABSTRACT

This article presents and discusses the results obtained from a convenience sample, using the snowball technique, of 35 Portuguese spinal cord injured persons, of any level, both genders and age between 18 and 55. Individual responses to 1 open question: "What is the impact of the injury in your affective relationship? Through the collection of individual data we have elaborated significant categories, thus constituting the group's discourse: Changes that require the reformulation of the affective relationship; Instability installed in the relationship and Comparing pre-injury. The main results emerged from the Grounded Analysis methodology and allowed the access to relevant issues, such as weakening the self-confidence, partner's decreased sexual interest, instability, and fear of abandonment. These concerns expressed the influence that the injury had on the construction of the subjects' perception of their affective relationship.

Key words: Medical illness, relationship factors, qualitative study.

INTRODUCTION

Spinal cord injury, traumatic or not, has important implications for personal, family and social life of people affected. If sexuality assumes a preponderant role in the daily lives of individuals and in building a solid structure in interpersonal relationships, then the impact of problems related to sex in a healthy person and in a couple can lead to unhappiness, frustration and loss of self-esteem, thereby affecting the essence of the relationship (Madorsky & Dixon, 1983). While many couples accept the limited sexual life as part of their new condition, others cannot adapt to sexual dissatisfaction and rush to a deep emotional crisis (McInnes, 2003). These additional complications can decrease the willingness of the individual to try out his/her new sexual condition (Sharma, Singh, Dogra, & Gupta, 2006).

METHODS

Thirty-five Portuguese subjects with spinal cord injury of any level and from both genders were intentionally recruited, using the snowball technique. The average age is 33.2 years, being 33.8 years the female average and 32.9 the male

average. With regard to gender, female represent 25.7 % and male 74.3 % of the injured. An open question was asked to each individual, in person, and his/her discourse was qualitatively analyzed, according to the Grounded Theory.

RESULTS

Question: "What is the impact of the injury in your affective relationship?"

This question gave rise to the main categories:

- a) Changes that require the reformulation of the affective relationship;
- b) Instability installed in the relationship, and
- c) Comparing pre-injury.

CHANGES THAT REQUIRE THE REFORMULATION OF THE AFFECTIVE RELATIONSHIP

In this category the subjects identify psychological and emotional changes in their affective relationship, resulting from the injury. These changes are identified as a whole and as being either negative or positive. A small proportion of these subjects, despite considering there were changes, didn't

classified them as negative or positive in their present life. This category includes the main conceptual categories: a) Changes in the relationship with positive impact; b) Changes in the relationship with negative impact; c) No impact; and d) Changes in the relationship without specification. Table 1

presents a systematization of the conceptual and descriptive categories that gave rise to the main category Changes that require the reformulation of the affective relationship as well as examples of the subjects' discourse.

Table 1- Systematization of the conceptual and descriptive categories considering the main category Changes that require the reformulation of the affective relationship.

Conceptual category	Descriptive category	Ref.	N
Changes in the relationship with positive impact		59	25
	Conversations on the topic	24	16
	Relevance of details	15	6
	Improved	6	4
	Security	5	5
	More unity between the couple	3	3
	More time	1	1
	Partner's patience	1	1
	Maturation	1	1
	Creation of future goals	1	1
	Commitment	1	1
	Valuing the partner's pleasure	1	1
Changes in the relationship with negative impact		57	23
	Shaken self-confidence	13	8
	Decrease in the interest of the partner	9	4
	Complications in the activities	8	4
	Lack of dialogue	5	3
	Emotional Dependency	4	4
	Changes in sexual	3	3
	Abandonment	3	2
	Emotional neglect	2	1
	Nonconformity	2	1
	Decreased desire	2	1
	Guilt	2	1
	Changes in behaviour	1	1
	Increased aggressiveness	1	1
	Changes in the nature of the relationship	1	1
Nervousness	1	1	
Changes in the relationship without specification		6	6
	Changes	3	3
	Minor changes	2	2
	Major changes	1	1
No impact		7	6
	No impact	4	3
	Everything's alright	2	2
	Normal relationship	1	1

In Changes in the relationship with positive impact 25 subjects, in 59 occasions, pointed out the fact of talking a lot about the situation with their partners and giving more importance to details than before as something very positive in their relationship. Overall, the discourse revealed that the relationship has improved, allowing more security and unity between the couple. Some subjects have now more time to his companion and pointed also to the other's patience, commitment and maturity of the relationship. The

establishment of future goals and appreciation of the pleasure of another field are also described as positive impact. Regarding the conceptual category Changes in the relationship with negative impact, 23 subjects, in 57 occasions, made reference to the shaken self-confidence and the perception of declining interest of the partner. Complications in the daily activities and entertainment, the lack of dialogue and emotional dependence, are also highlighted as negative changes. Other negative aspects are

focused on the changes in terms of sexual life, as well as decreased libido. The abandonment and emotional neglecting of the other perceived by the subject are also reported events. Finally, behavioural changes verifiable in the subject, such as blaming the increased aggressiveness and nervousness, are factors contributing to the emergence of problems in the relationship. In the category No impact, 6 subjects, in 7 occasions, assumed that the injury did not cause any impact on the relationship, keeping all within normal limits before. In the conceptual category Changes of the relationship without specification 6 subjects, in 6 occasions, pointed vaguely to changes but without any specification.

INSTABILITY INSTALLED IN THE RELATIONSHIP

In this main category the subjects identified factors caused by the accident, which they think exist in the context of the relationship and that can be symptoms of instability between the couple. The only emerging conceptual category has the same name of the main category, i.e., Instability installed in the relationship. 17 subjects, in 26 occasions, took that fear of abandonment, separation between the couple, their distance and the uncertainties regarding the construction of a future together, are negative aspects that arose within the relationship as a result of the traumatic event. Still, others mentioned the lack of emotional connection, so we didn't collect any discourse on this issue.

Table 2 Systematization of the conceptual and descriptive categories considering the main category Instability installed in the relationship

Conceptual category	Descriptive category	Ref.	N
Instability installed in the relationship		26	17
	Fear of abandonment	16	13
	The distance between the couple	4	3
	Lack of affective relationship	3	2
	Avoidance	2	1
	Uncertainties concerning the future as a couple	1	1

COMPARING PRE-INJURY

In this main category, 5 subjects, in 8 occasions, expressed the great differences between the way they perceived themselves before the accident and at the present moment. They referred to the ease and simplicity of the relationship previously the traumatic life-event, and the feeling of nostalgia.

Table 3 Systematization of the conceptual and descriptive categories according to the main category Comparing pre-injury.

Conceptual Category	Descriptive category	Ref.	N
Comparing pre-injury		8	5
	Things have changed	4	3
	Before it was simple and easy	3	2
	I miss how my life was before	1	1

DISCUSSION:

Studies confirm that the quality of the affective relationship of individuals with spinal cord injury is a positive variable and a predominant factor in a favourable holistic rehabilitation (Kreuter, 2000). Therefore, this question sought to assess the impact of traumatic events in the dynamics of the relationship and consider the possible consequences involved. We considered as main categories: a) Changes that require the reformulation of the affective relationship, b) Instability installed in the relationship; and c) Comparing pre-injury.

CHANGES THAT REQUIRE THE REFORMULATION OF THE AFFECTIVE RELATIONSHIP

In this category, the vast majority of people assumed that, due to injury, there were changes in their affective relationship. Whether having a positive or negative impact, the subjects identify several events that forced the reformulation of the relationship. Others have referred to general changes, without specifying the nature of these changes, and a minority revealed that the relationship remains normal, without any impact. On the positive changes, among other things, participants identified the exchange of views on the new condition as an important aspect.

(...) we talk about things now that we didn't talk before. [S8]

(...) My wife and I talk a lot about all this. [S31]

It seems common that the partners of the injured spinal cord tend to reshape the roles and accept the participatory and open communication about sexual issues (Beauregard & Noreau, 2010), including seeking to have conversations about how the consequences of the injury may affect the relationship, once it has become a new aspect of the union and may challenge it in an unpredictable way (Ostrander, 2009).

(...) many times I ask him if he did not want another life. [S21]

Another aspect considered by the participants that promoted positive changes was the importance they began to give to certain details that were previously neglected, and that's why they now consider that their relationship has improved. For some injured the analysis of the consequences of injury in terms of sexual life, lies in the belief that people became more attentive to the partner and to the relationship itself (Ostrander, 2009).

(...) Now I value some things that I didn't value before. [S4]

(...) Now give more attention to other things which before we did not care much. [S7]

(...) I pay more attention to details in my affective relationship. [S11]

After the occurrence of the injury, the subjects' discourse tend to be a description of improvement in the relationship, arguing that this improvement is due to an increase of intimacy that provides a range of other valued aspects on both elements of the couple (Rohrer, 2001). By having a

strong commitment to the relationship, over time the subject eventually will return to the normal pattern of the relationship existing before the injury, or even register the improvements mentioned.

(...) I think now is better. [S13]
 (...) I think we're even better. [S12]

The union of the couple and security transmitted by the partner are also mentioned by some participants, suggesting that the occurrence of the injury led to a stronger link. In many occasions the subjects and their relatives use similar strategies to address the problem, so in this sense they become closer and the relationship tends to become stronger (Martins Pereira & Cavalcanti, 2006).

(...) we are closer now. [S8]
 (...) it brought us closer. [S13]
 (...) she is my support and I am her support. [S8]
 (...) he tries to make me feel self-confident... uh ...he doesn't want me to be insecure. [S24]

Notwithstanding the statements of improving relationship, several other subjects reported many different concerns. The fear and insecurity that comes from a new physical condition, perceived as a capital loss, was also found in the subjects' discourse.

(...) I am very afraid of not being enough to her. [S27]
 (...) I know she is not totally fulfilled, and it must be very bad to have a cripple in her life. [S31]
 (...) Even if he is patient now, he may not be it forever. [S32]

The changes that occur after a spinal cord injury contribute to the reduction of self-acceptance, self-confidence and self-esteem. The main argument relates to the use of a wheelchair, which is associated with body image, which may compromise the physical attractiveness and hinder the establishment of relations for which physical attractiveness is considered an essential requirement (Murta & Guimarães, 2007). Thus, the development and maintenance of affective relationships can be a source of stress for the spinal cord injured, who might feel fear of abandonment (FÍSICA, 2004). Changes in the sexual life are also visible and marked by individuals as a factor of imbalance in the relationship.

(...) sexual life is very important and that's not going well. [S30]
 (...) our sexual life has changed considerably. [S32]

In the descriptions of the subjects it was noticed that the decrease in desire negatively influences the dynamics of romantic involvement and sexual life. This may occur unilaterally or bilaterally and prove to be a predictor of marital dissatisfaction.

(...) I think she doesn't get excited with me. [S1]
 (...) when we have sex she says many times that she doesn't know what she's doing, if I'm not feeling anything. [S5]
 (...)I feel that she makes a sacrifice to have sex with me and I angry with this. [S10]

(...) now I do not feel much need to have sex. [S28]
 (...) my desire is no longer the same, and that's enough to make not so available. [S32]

It seems generally agreed that sexual desire is presented as a key factor in influencing relationship satisfaction and subsequent behaviour adjusted in the dynamics of the relationship. Also, the perception of the partner's dissatisfaction, results in a decreasing interest in sexual activity (Phelps, Albo, Dunn, & Joseph, 2001). One of the predictors of a full and active sexual life is the varied repertoire of rewarding sexual expressions and the concern about the not injured partner's sexual pleasure (Murta & Guimarães, 2007). What happens in most cases is that the partner takes the role of caregiver and in fulfilling this dual role of caregiver and lover, which can originate situations of decreased sexual interest (Kreuter, 2000). Behaviour changes, including increased aggressiveness, were also reported by participants as factors that can disrupt the affective relationship.

(...)I become aggressive in conversation, something I wasn't before. [S3]
 (...)There was a time when I was very upset... uh ... I was aggressive and she had to bear the consequences. [S10]

The adjustment to spinal cord injury causes profound emotional changes in personality, which is also mediated by pre-morbid characteristics. Other factors may also cause changes in behaviour of the spinal cord injured that present as foreign to his personality, particularly the lack of a solid social support, isolation, pain and even some medications (Dezarnaulds, 2002). The changes found in the subjects' behaviour after a spinal cord injury are identified as more negative than positive (Venturini, Decésaro, & Marcon, 2007). Despite the fact that only a few subjects reported that the injury did not cause any impact on their affective relationship, this kind of discourse was actually found in this study. This can be explained by the fact that after a spinal cord injury, the relationships are not affected as much as one might think, because the partner's feelings are, likewise, affected by the traumatic life-event (Kreuter, 2000). Thus, the support and effective communication between partners can be crucial to overcome the possible imbalances that may arise from the event.

(...) for now I think everything is great. [S2]
 (...) for now we have overcome all. [S29]
 (...) all is peaceful within that daily routine. [S30]

Finally, there are some references to changes but without concrete specifications concerning the type or level in which they occurred, however, they might suggest a pejorative meaning.

(...) I think something has changed, very slightly, but still a change. [S5]
 (...) many things changed. [S21]
 (...) our life changed on many levels. [S32]

It is reported that this incapacity carries with it the likelihood of causing complex changes in subjects' lives and

in their affective relationships (Oliveira, 2004). The presence of physical impairment and disability changes the relationship's dynamics and complexity of the interactions, whether positive or negative, which imply the implementation of new routines in everyday life (Venturini et al., 2007).

INSTABILITY INSTALLED IN THE RELATIONSHIP

In this category the subjects' narratives tend to show uncertainty regarding the course of the relationship by assessing about themselves some avoidance and removal, as can be seen in the discourse of subject 22: "Time went by and ... you know ... everything goes away ... Sometimes it seems we are very distant." This behaviour can be closely linked to the condition they are in, i.e., the fear of being abandoned may be behind this behaviour.

(...) I'm afraid of losing her, that she can get a man without any incapacity. [S4]

(...) Sometimes I'm afraid... that she might dismiss me. [S10]

(...) I'm always afraid of being abandoned. [S31]

(...) I'm afraid to give myself so I won't suffer. [S33]

The reorganization of everyday life after a spinal cord injury may force the couple to change the dynamics of the relationship, thus being able to put it at risk and experience difficulties in keeping it (Kreuter, 2000). The uncertainties regarding the future of the relationship are identified by the subjects 18 and 19:

(...) She gets tired too and she will get more tired as time passes. [S18]

(...) Do not know if the love we feel for each other is enough to keep her a long time by my side... like to get married or so. [S19]

Some authors suggest that spinal cord injury affects mainly relationships from before the event because they face different tasks in adapting to the new condition, such as readjustment of roles and offer emotional and instrumental support in acute injury from their partner. Marriages performed after the injury already start with the limitations established and probably the injured is completely adapted to his/her new condition (Chan, Lee, & Lieh-Mak, 2000). The most common predictive factors for affective relationships' longevity after injury are the social and professional integration of the subject and self-perceived health (Murta & Guimarães, 2007). Contrary to expectations, the level of injury, function, mobility and independence are not described

as significant predictors for any disruption (Karana-Zebari, de Leon, & Kalpakjian, 2010).

COMPARING PRE-INJURY

Again, this issue also contained notes comparing the situation before and after the event. Nostalgia was evident in the subjects' discourse and demonstrates the difficulties in accepting the new condition. These references relate to the feelings of the spinal cord injured and what he thinks his/her partner feels.

(...) I miss how it was before. [S21]

(...) I know that my partner misses how it was before. [S24]

(...) When I'm having sex I always remember how it was before and feel sad. [S32]

According to this type of feeling, neither the subject nor the family are ready for this development and therefore denial is common. So, it normally takes some time, going through various stages in the search for adaptation, and during that time nostalgia of the past is always very present (Chen & Boore, 2009).

CONCLUSION–GROUP'S DISCOURSE

On the other hand, in terms of impact on the affective relationship, the subjects reported increased dialogue between the couple, however, weakening the self-confidence and the perception of the partner's decreased sexual interest, presented as negative factors in the relationship and leading to instability, mainly by fear of abandonment. To try to overcome these feelings of insecurity, the experience of the partner's pleasure as if it was his/hers, became the main goal and led the subjects to commit to their partners' sexual satisfaction, as they report having lost the ability to achieve moments of sexual peak as before. However, even though they use the investment as a strategy to reduce the emotional costs of their new condition, individuals do not cease to experience negative feelings during sexual contact. The threat of poor sexual performance has great importance when sexual activity becomes an event that generates anxiety, depressive states and general dissatisfaction, leading, inevitably, to an unsatisfactory experience of sexual intercourse. During the rehabilitation process it is important to clarify the patient and his partner's about the need for greater mutual cooperation and even the reevaluation of their sexuality, which foster the achievement of sexual satisfaction of both parties. The recovery of sexual ability is an important prerequisite to obtain a personal and family balance, and that eventually may lead to the step of procreation, which deserves a special attention.

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